



**The Rare Chromosome Disorder Support  
Group**

**Report and Financial Statements**

**31 March 2006**

## Legal and Administrative Details

For the Year Ended 31 March 2006

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<b>Status</b>	The organisation is a registered charity, registered on 5 August 1993	
<b>Governing Document</b>	The charity is constituted under a trust deed dated 24 July 1993.	
<b>Charity Number</b>	1024624	
<b>Registered Office</b>	179 Bakers Ground Stoke Gifford Bristol BS34 8GE	
<b>Trustees</b>	Edna Knight Gillian Manvell Marie Layng	
<b>Management Committee</b>	Carey Hunt Sarah Trevitt Eleanor Fiske Michael Patterson	
<b>Staff</b>	Beverly Searle Marion Mitchell Prisca Middlemiss Lydia Dickie Julie Griffin	Development Director Family Support Officer Information Officer Assistant Information Officer Finance Officer
<b>Medical Advisor</b>	Professor Maj Hulten	
<b>Bankers</b>	National Westminster Bank Plc PO Box 9 1 Upper Market Square Hanley Stoke-on-Trent St1 1QA	Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA
<b>Auditors</b>	Godfrey Wilson Ltd Chartered Accountants & Registered Auditors 48 West End Minchinhampton Gloucestershire GL6 9JA	

The trustees are pleased to present their report and audited financial statements for the year ended 31 March 2006.

Legal and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the memorandum and articles of association and the Statement of Recommended Practice – Accounting and Reporting by Charities (issued in March 2005).

## **Structure, Governance and Management**

The Rare Chromosome Disorder Support Group, known as “Unique”, became a registered charity on 24 July 1993.

A board of trustees is responsible for the overall governance of the charity. Trustees are either named within the constitution or are elected. Unique has three trustees and a management committee of seven members (including trustees) which meets with staff and the charity’s chief medical advisor at least four times a year to review the group’s work and formulate strategy. Unique also benefits from the services of professional medical advisors who liaise with the charity’s employees.

Unique employs five members of [staff](#) two full-time and three part-time. The charity benefits from the donated services of members who use their professional skills and knowledge to assist the group in areas including ICT, fundraising, marketing, creative design, copywriting, HR and legal advice as well as with general administrative support. The Development Director is responsible to the management committee for the day to day operations of the charity and implements policies agreed by the board of trustees. The Finance Officer assists the Development Director in financial matters.

A risk register is maintained to identify and monitor implications for the charity should its main strategic goals not be achieved or operating conditions change. The register is under review, with contingency plans to deal with challenges that might arise.

The response from families and professionals to the work of Unique is logged and reviewed continuously. Feedback arrives by letter, telephone, email and via the private members’ forum of the Unique website or through information submitted for publication in the charity’s magazine. The introductory pack sent to new inquirers contains a basic evaluation form and service guide sheets. More detailed evaluation forms are included with letters sent out by the Assistant Information Officer and in conference and study day packs. The direction of future work is influenced by feedback from members.

### **Company limited by guarantee**

At a general meeting of members of the Rare Chromosome Disorder Support Group on 23 April 2005, an extraordinary resolution was passed accepting the trustees’ proposal to transfer the assets, liabilities and activities of the charity to a newly formed company limited by guarantee. Unique RCD Ltd, sharing the aims and objectives of the original charity, was duly incorporated on 23 May 2005 with the approval of the Charities Commission. Subsequently the company name was changed to Rare Chromosome Disorder Support Group and registered in England & Wales as company number 5460413, charity number 1110661. At the date of writing this report, the transfer of the assets, liabilities and activities from the original charity to the company limited by guarantee had been completed.

## Objectives and Activities

### Objects

Unique aims to provide links between families whose children have similar clinical and/or practical problems caused by [rare chromosome disorders](#). A rare chromosome disorder causing disabilities and health problems can occur in at least one in every 1,000 live births. The overall figure for any rare chromosome disorder (including balanced rearrangements that do not cause disability and ill health) is at least one in 200 live births.

Unique aims to raise awareness of rare chromosome disorders, their high incidence and their significance, both in the UK and overseas, and works closely with professional contacts.

### Activities

Unique's core charitable activities are categorised under two primary headings:

1. [Family Support Services](#)
2. [Awareness Raising](#).

#### 1. Family Support Services

Unique acts as an international support group and aims to provide the following core services on an ongoing basis:

- A high-quality magazine produced three times each year and distributed to members. This publication is the 'face' of Unique to many families.
- A comprehensive website at [www.rarechromo.org](http://www.rarechromo.org), which attracts the worldwide rare chromosome disorder community to Unique.
- A [24-hour helpline service](#) to support families needing information and to relieve parents and carers in times of distress and isolation.
- An annual conference held in the UK to bring together families and professionals and share knowledge of advances in diagnosis as well as information helpful in the daily lives of those affected by a rare chromosome disorder.

To provide the core support group services, Unique has developed the following resources:

- A confidential offline database updated at least once a year, which keeps individual records showing the lifetime effects and consequences of specific rare chromosome disorders on each affected member of Unique. This constitutes a unique resource that is not available anywhere else in the world. The Unique database manager uses the data to respond to requests for information from clinical geneticists, researchers and other professionals as well as from families and people with rare chromosome disorders.
- The Unique [information project](#), which builds on our range of published material to support more families affected by rare chromosome disorders
- Indirect family support delivered via [professionals](#) which builds on our existing relationships with professional bodies and individuals working with families affected by rare chromosome disorders, including contributions to medical research into the effects and health issues relating to rare chromosome disorders.

## 2. Awareness raising

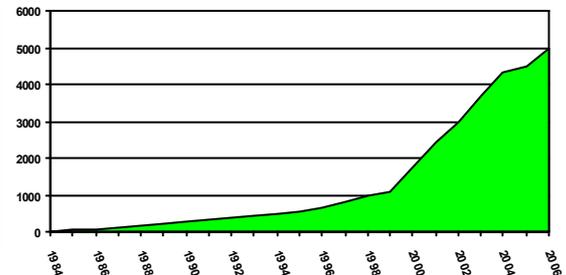
Unique aims to educate the general public about rare chromosome disorders through talks and presentations and using national and local media when appropriate.

## Achievements and Performance

### 1. Family Support Services

[Membership of Unique](#) continues to grow at a steady rate, illustrated by the following figures.

	31 March 2004	31 March 2005	31 March 2006
Family Members (cumulative)	4,000	4,500	4,920
New families	488	412	400
Total countries	64	65	68



## Magazine



We publish a highly acclaimed magazine three times a year in which families and professionals share their knowledge and experiences. The magazine contains information on topics such as health-related, behavioural and disability issues and how to cope with them, relevant disability and health legislation, financial and benefits information and education for children with special needs, as well as a focus on advances in genetic knowledge and testing and reproduction options. The full-colour magazine is professionally produced to a high standard. Each issue costs £10,000 to produce and distribute to members.

A special edition of the magazine brought information from the October 2005 conference to 4,800 member families worldwide.

Website: [www.rarechromo.org](http://www.rarechromo.org)

	31 March 2004	31 March 2005	31 March 2006
Website 'hits'	87,798	119,569	170,193
Messages posted on members' forum	2,000	2,352	2,876

Members can go to "collect" an electronic version of the magazine from the new magazine archive held in the password-protected part of the website. So far over 500 member families have chosen the electronic delivery route, saving the group a considerable sum in postage and printing costs.

The Development Director and her husband, an IT consultant, worked throughout the year to develop the new website, launched in March 2006. Over 50 booklets and flyers about rare chromosome disorders can be accessed through and downloaded from the password-protected members' area with many more to come, along with new areas for professionals and 'Friends of Unique'.

Over 200 hours were donated by Trevor Searle to develop the site in addition to the regular hours he devotes to developing and maintaining the Unique database and ICT capacity. Mr Searle's professional time dedicated this year alone to the charity has been valued at £20,000.

## Helpline

	31 March 2004	31 March 2005	31 March 2006
Telephone enquiries (cumulative)	4,500	5,200	6,000
Email enquiries (cumulative)	32,146	49,560	73,200

The Development Director continues to support the 24-hour helpline and acts as the initial point of contact for all new families.

## Conference

The 11th Unique conference took place from 21 to 23 October 2005 at the Daventry Hotel, Daventry, UK. The conference attracted eminent professional speakers and workshop leaders as well as over 250 family delegates. The focus was on advances in genetic testing and diagnosis. Workshops were held on other issues pertinent to families' daily circumstances, such as sleep disorders and challenging behaviour. Its net cost to Unique for 2005 was under £10,000.

A [conference report](#) is available to the public on the home page of [www.rarechromo.org](http://www.rarechromo.org) – the charity's website.

## Trustees' summary

The trustees are delighted by the excellent outcomes of the charity's Family Support Services. The Unique magazine continues to be an excellent production and has evolved significantly from its beginning as a basic newsletter. The 11<sup>th</sup> Unique conference was a highly successful weekend and the feedback from members proves it to be a worthwhile activity that is valued immensely. Thanks go to the Family Support Officer who works tirelessly to ensure that each conference is even better than the last. It is regrettable that insufficient income prevents Unique from holding the conference annually.

The trustees recognise that the huge frontline response to families, much of it bespoke, is generated by a tiny number of highly dedicated staff. Thanks are due to all employees who work hard to support families by providing prompt information and creating opportunities for social contact to relieve often profound feelings of isolation. Special mention must be made of the long hours put in by the Development Director herself to provide an instant response of the highest quality to every inquiry. To provide more support to staff performing an invaluable service is at the heart of trustees' current concerns over resources.

## Maintaining the Unique Database

Unique maintains a comprehensive offline database detailing lifetime effects of specific chromosome disorders on individual members, providing an invaluable source of information for new and existing members and professionals. From the database, staff are able to provide inquiring professionals with anonymised information about the effects of a specific rare chromosome disorder. This is particularly helpful when there is no Unique information leaflet on a specific condition. Feedback from professionals, especially geneticists and paediatricians, has demonstrated that this service has proved invaluable to them in counselling and managing affected families.

An anonymised shortened version of the full Unique database is held on the public website, allowing professionals and families themselves to search through the specific rare chromosome disorders ([with karyotype](#) where available) of every affected member in the group.

The database was redesigned in 2005 to accommodate more detailed information about individual members than before. We anticipate providing an increasing amount of assistance to research projects in future, at all times protecting members' confidentiality.

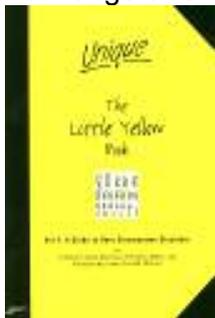
## Information Project

For three years the Information Officer has researched and produced family-friendly, medically verified [leaflets and flyers](#) on more than 60 specific chromosome disorders. Most of these are now available to our members via a password-protected area on our website.

Chromosome disorder booklets and flyers available from Unique to date include:

<ul style="list-style-type: none"><li>• Pallister Killian syndrome</li><li>• Mowat Wilson syndrome</li><li>• Robertsonian translocations</li><li>• Jacobsen syndrome</li></ul>	<ul style="list-style-type: none"><li>• XYY introduction syndrome</li><li>• XXYY syndrome</li><li>• XYYY syndrome</li><li>• XXYY syndrome</li><li>• XXXXY syndrome</li><li>• Pentasomy X</li><li>• Tetrasomy X</li></ul>	<ul style="list-style-type: none"><li>• Mosaic trisomy 16</li><li>• Trisomy 8 Mosaicism</li><li>• Trisomy 9 Mosaicism</li><li>• Uniparental Disomy 14</li><li>• Diploidy triploidy</li><li>• Triploidy</li><li>• Idic 15</li></ul>	<ul style="list-style-type: none"><li>• Ring 2</li><li>• Ring 13</li><li>• Ring 14</li><li>• Ring 15</li><li>• Ring 18</li><li>• Ring 20</li><li>• Ring 21</li><li>• Ring 22</li></ul>	<ul style="list-style-type: none"><li>• 1q duplications</li><li>• 4p duplications</li><li>• 5p duplications</li><li>• 7q duplications</li><li>• 8q duplications</li><li>• 8p duplications</li><li>• 8p Inv dup del</li><li>• 9p duplications</li><li>• 17p duplications</li></ul>	<ul style="list-style-type: none"><li>• Deletions 1p36</li><li>• 1q4 deletions</li><li>• Deletion 2q37</li><li>• Deletion 3p25</li><li>• 3q2 deletions</li><li>• 5q22 deletions</li><li>• 6p deletions</li><li>• 7q36 deletions</li><li>• Deletion 8p23.1</li><li>• 9p deletions</li><li>• 10q26 deletions</li><li>• 11p deletions</li><li>• 13q deletions</li><li>• 21q deletions</li></ul>
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The full range of Unique publications includes:



- [Little Yellow Book - volume 1](#), a guide to rare chromosome disorders for families and non-genetics professionals. The book translates technical terminology and complicated scientific concepts into accessible language.
- [Unique Tales](#), a cartoon strip aimed at 7 to 10 year olds to help explain rare chromosome disorders to siblings of affected children.
- **Volume 2** of the **Little Yellow Book** series continued to evolve over the last 12 months and is near completion. Publication was delayed to include details of new molecular techniques such as DNA microarray technology. Illustrations for the book are complete and the book should go to print in Summer 2006.

The Assistant Information Officer has prepared articles for the magazine on a wide range of topics affecting families' daily lives (e.g. [carers'](#) and disability legislation, [educational issues](#) and [communication for disabled children](#)). They are available from the public pages of our website.

Additional Unique leaflets on subjects of particular interest to our member families include:

- [Behaviour](#), completed and verified by a consultant psychiatrist, Dr Sarah Bernard and a behavioural therapist, Natasa Momcilovic based at the Michael Rutter Centre, London.
- Discrimination, almost completed; Dame Philippa Russell, a Disability Rights Commissioner and eminent campaigner has kindly agreed to verify it

### **Trustees' summary**

The Trustees are very grateful to the Information Officer and Development Director for their commitment to producing the range of information on specific rare chromosome disorders that we have to date. The information project is the jewel in our crown as it provides a truly unique service to these families and the professionals supporting them. It is the trustees' intention that the information project should continue and to that end, some funds have been secured. Additional investment will be sought to ensure expansion.

We are grateful, too, to the Assistant Information Officer for the quality of her response to families' need for more general information on issues that affect their lives with children who may develop multiple and complex needs including highly challenging behaviour that is often misunderstood by the wider community. The response from other disability support groups indicates how valued her work has been and the trustees hope to be in a position to continue to provide this service when the dedicated grant runs out in 2006.

### **Indirect Family Support delivered via Professionals**

Unique informs professionals, including geneticists, GPs, paediatricians, special needs teachers and social workers, health visitors, community paediatric nurses and midwives as well as members of other support groups, on how the group offers information and support when a family is newly diagnosed. This has been achieved in a number of ways:

- Unique has carried out a targeted awareness-raising mailshot in the UK aimed at any professionals who might come into contact with families and individuals affected by rare chromosome disorders.
- Unique has given numerous presentations to professionals over the past 12 months and has been invited to contribute as expert patient representative to a number of professional committees and working groups. Although by no means exhaustive, examples include:
  - presenting to midwives and young cytogeneticists attending the first three genetics education courses run by the London Genetics Knowledge Park at the Institute of Child Health (ICH) in London, as well as presentations to clinical, molecular and cytogeneticists in various regional genetics centres
  - representing Unique on the Cambridge Genetics Knowledge Park's learning disability and genetics project.
- Unique has been pivotal in helping to develop a virtual network ([Eurochromnet](#)) of RCD support groups across Europe aimed at raising awareness and spreading high quality information and best practice across the Continent, while breaking down language and cultural barriers. Unique is an active member of the European Rare Diseases Organisation and provides advice to the Human Genetics Commission.
- Unique has presented at the British Society of Human Genetics Annual Conference and, for the last three years, was invited to participate with an awareness-raising stand that attracted widespread attention. The majority of delegates were clinical geneticists, genetic counsellors, genetic nurses, cytogeneticists and molecular geneticists from across the UK, as well as from abroad.

Unique is a partner in two pan-European projects involving a wide range of genetics professionals and researchers:

- Unique was invited by the co-ordinator Professor J-J Cassiman of the University of Leuven in Belgium to become a partner in a successful bid for funding from the EC for a network of excellence entitled [Eurogentest](#) (Genetic Testing in Europe – Integrated Network for test development harmonisation, validation and standardisation of services). Participation in this network has led to some excellent contacts in the genetics world in Europe and beyond and has prompted many families to come to Unique for help.

- Unique is a partner in a second EC project, [SAFE](#) (Special Non-Invasive Advances in Foetal and Neonatal Evaluation), a network of excellence involving 50 research groups from across Europe investigating non-invasive methods of testing and diagnosis for genetic abnormalities both *in utero* and in the neonatal stage.
- Unique works co-operatively with colleagues from the Advisory Panel of the UK Rare Disorders Forum and from WellChild ([www.wellchild.org.uk](http://www.wellchild.org.uk)). The main involvement is in developing the proposed Rare Disorders Mapping Project in the UK and the recently launched rare disorders forum website. This new website aims to be a platform for exchange of knowledge and best practice among rare disorders support groups across the UK.

### **Trustees' summary**

The trustees are pleased that relationships with key professionals keep the group expanding and enhance the quality of its work and reputation. We are proud of the reputation that Unique has developed among genetics and other professionals, due entirely to the knowledge and skills of our key staff. Unique could not operate without support from the medical professionals who work with affected families and will continue to invest resources in this important area.

## **2. Awareness Raising**

Unique runs a UK and global network of local contacts who distribute the group's awareness-raising posters and information leaflets to local hospitals, social work departments, doctors' surgeries and special schools. New members receive an introductory pack with awareness-raising literature to distribute in their local area.

Unique is promoted on innumerable public information databases and has established good working relationships with [Contact a Family](#) (CaF) and the [Genetic Interest Group](#) (GIG). Both CaF and GIG refer families and individuals affected by rare chromosome disorders to Unique.

Unique raises awareness of rare chromosome disorders and of the support group through local and national media and actively encourages families to mention Unique in any press articles or radio or television interviews in which they may get involved.

### **Trustees' summary**

The trustees are pleased with the positive results from contacts made with genetics professionals and other support groups as well as with the wider world. Tailoring Unique's resources to its income will continue, however, to restrict expansion of Unique's existing capacity and until income increases, publicity campaigns must remain reactive rather than proactive. It is important that Unique's ability to offer a first-class service to new and existing family members remains unimpaired. Without more resources, Unique would not be able to respond to the results of a high-profile advertising campaign, however desirable this might be from the perspective of all families with a chromosome disorder and of those who support them.

## **Financial Review**

### **Main Sources of funding**

#### **1. Donations and Gifts**

Primarily unrestricted income received from members, their friends and family. There has been some small increase this year in corporate donations from members' employers. Regular giving also increased slightly this year due to raised awareness of the need for funds among members.

#### **2. Volunteer Fundraising**

Unrestricted income from the activities of individual members who organise local events such as coffee mornings, cake sales, etc. or who take part in national sponsorship events such as the London Marathon and Great North Run.

### **3. Internal Fundraising**

Unrestricted income generated directly from the sale of Christmas Cards and merchandise to Unique members and their family and friends. Advertising to members is principally through the Unique magazine and website.

### **4. Grants**

Unique was particularly grateful to receive a number of grants this year. Donors included:

- The Health Foundation ~ contributes to the running costs of the information project
- Children in Need ~ restricted funding to support the Assistant Information Officer's post
- VICTA ~ contributes to the Family Support Officer's post.

### **5. Interest and Investments**

Income is generated from bank interest and Gift Aid.

In September 2005, two Tracey Emin prints, "Little Family", were donated to Unique, valued independently at £700 each.

### **Trustees' summary**

The trustees would like to thank everyone who contributed to the work of Unique, whether through fundraising, donations or grants. We rely heavily on voluntary income to carry on the valuable work of supporting all Unique families. It is our view that costs associated with fundraising activities have been low.

We should like to comment on the significant reduction in income during 2005/6 compared to the previous year. In 2004/5 Unique was exceptionally fortunate to receive major grants. In 2005/6, like most other UK charities, we saw the value of donations from the public reduce dramatically in response to worldwide natural disasters.

In light of the environmental factors beyond our control, the trustees decided that for a limited period, it would be appropriate to use the charity's reserves to ensure that services were maintained at their existing level so that no beneficiary family was affected.

In this situation, the trustees wish to thank particularly the Finance Officer, who has prepared prompt and detailed monthly management accounts to enable us to take well-informed strategic decisions about the group and its ongoing commitments. As well, she has played a leading role in the ongoing search for funds to enable the group to continue its vital work. Again, this staff member works hard far beyond the number of hours for which she is paid by the group and we value her efforts highly.

In 2006/7 the trustees will focus attention on a growth strategy for the charity to secure its long-term future.

### **Expenditure**

#### **Family Support Services**

Costs associated with the magazine are proportionate to the increase in membership, the increase in content of the magazine and related postage costs. Website and helpline running costs continue to be managed efficiently and as mentioned previously are subsidised significantly by voluntary support. The Unique conference was delivered within the agreed budget and subsidised by fees charged to attending member families as well as by donations and fundraising. Additional investment would be required to support an annual conference.

The cost of maintaining the Unique database has been significantly under-resourced. Next year, investment in the database will be urgently required to maximise the potential of this irreplaceable asset.

The information project has delivered well above the expected outcomes. Sixty booklets exceeded the original 40 planned for the end of March 2006. The quantity of database information could yield hundreds of condition-specific publications. Additional investment is required to extend the capacity of the information project and to run study days on individual rare chromosome disorders.

Resources used to support families via professionals are within budget. With additional expenditure, the service could be extended to provide more information and support to professionals serving the rare chromosome disorder community.

### **Awareness Raising**

Considering that there are just two full-time employees representing Unique at a significant number of events and seeking further opportunities to present to a wide range of audiences, the trustees are particularly pleased with the outcomes achieved in relation to the relatively low expenditure.

### **Gifts in Kind**

Like many charities, Unique relies heavily on the generosity of individuals who contribute their professional expertise free of charge. The trustees wish to extend their sincere thanks to all these generous supporters and to mention particularly the following individuals:

Trevor Searle, for his expertise, time and inexhaustible patience spent on improving and maintaining the Unique website and online capabilities. Without this free in-house resource, Unique would not have been able to develop and maintain its website and database.

Professor Maj Hulten, who has been a major influence and support in the work with EC partners as well as spending countless hours checking and verifying Unique's publications on specific disorders.

Carey Hunt, who provides her professional creative skills to design the excellent Unique publications.

Eleanor Fiske, committee member and director/secretary of the new charitable company, whose professional experience and energy ensured a smooth transfer to the new company limited by guarantee and who continues to freely provide both legal and secretarial advice to the group.

Michael Patterson, committee member and now director, who provided sound governance advice and produced the charity's first formal risk register.

Governance costs have been kept to a very low level. Trustees rarely claimed expenses and travel and meeting costs have been minimal.

The trustees wish to thank, too, the busy volunteers who continue to despatch the magazine three times a year, a Herculean task, as well as those members who gave of their time to help out behind the scenes to make the 2005 conference such a success.

## **Reserves Policy**

The trustees aim to hold between 3 and 6 months of expenditure in reserves, which equates to £45,000 to £95,000 in general funds. At this level, the trustees feel that they would be able to honour current commitments in the event of a significant drop in income. At 31 March 2006, unrestricted funds of £86,303 were held, which is in line with the reserves policy.

## **Plans for the Future**

The Trustees' immediate plans for the future include:

- Continuing to provide existing support for families affected by rare chromosome disorders in order to relieve feelings of isolation and despair.
- Expanding services to meet the growing demand from both existing members and new members each year.
- Continuing to develop the information project and to increase income to permit an expansion of this service while reducing the current unreasonable burden on existing staff who work well beyond their paid hours to meet needs.
- Developing a strategy to make the charity's core activities: helpline, magazine, database and information project self-sustaining.
- Developing an operating plan to boost income in order to fulfil the objectives of the charity on a long-term basis.

In March 2006 Unique began working with Pilotlight, a non-profit organisation marrying business mentors to charities wishing to develop their operations. The trustees are pleased to report that in their view, the emerging relationship with Pilotlight holds promise for the future of Unique.

## **Statement of Responsibilities of The Trustees**

The trustees are required to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charitable company and of its incoming resources and application of resources, including the net income or expenditure, for the period. In preparing those financial statements the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of charity and which enable them to ensure that the financial statements comply with the Charities Act 1993. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

**The Trustees**

The trustees who served during the year and up to the date of this report were as follows:

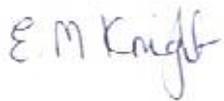
Edna Knight  
Gillian Manvell  
Marie Layng

The trustees have no beneficial interest in the charity.

**Auditors**

Godfrey Wilson Limited were re-appointed as the charity's auditors during the year, and they expressed their willingness to continue in this capacity.

Approved by the trustees on 1 July 2006 and signed on their behalf by

A handwritten signature in blue ink that reads "E M Knight". The signature is written in a cursive style with a large initial 'E' and 'M'.

Edna Knight - Group Co-ordinator

## **Independent Auditors' Report**

**To the Trustees of**

**The Rare Chromosome Disorder Support Group**

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We have audited the financial statements of The Rare Chromosome Disorder Support Group for the year ended 31 March 2006 which comprise the statement of financial activities, balance sheet and related notes. These financial statements have been prepared in accordance with the accounting policies set out therein and the requirements of Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005).

This report is made solely to the trustees, as a body, in accordance with section 44 of the Charities Act 1993. Our audit work has been undertaken so that we might state to the trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the trustees as a body, for our audit work, for this report, or for the opinions we have formed.

### **Respective Responsibilities of The Trustees and Auditors**

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law, United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and the Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005). The responsibilities of the trustees are set out in the statement of responsibilities of the trustees.

We have been appointed as auditors under section 43 of the Charities Act 1993 and report in accordance with regulations made under section 44 of that act. Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland).

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Charities Act 1993. We report to you whether, in our opinion, the information given in the trustees' report is consistent with the financial statements. We also report to you if the charity has not kept proper accounting records, or if we have not received all the information and explanations we require for our audit.

We read other information contained in the annual report, and consider whether it is consistent with the audited financial statements. This other information comprises only the report of the trustees. We consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the financial statements. Our responsibilities do not extend to any other information.

### **Basis of Opinion**

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of financial statements, and of whether the accounting policies are appropriate to the charity's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

### **Opinion**

In our opinion:

- the financial statements give a true and fair view, in accordance with United Kingdom Generally Accepted Accounting Practice as modified by the Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005), of the charity's state of affairs as at 31 March 2006 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- the financial statements have been properly prepared in accordance with the Charities Act 1993; and
- the information given in the trustees' report is consistent with the financial statements.



1 July 2006

**GODFREY WILSON LIMITED**  
Chartered Accountants &  
Registered Auditors  
48 West End  
Minchinhampton  
Gloucestershire  
GL6 9JA

## The Rare Chromosome Disorder Support Group

### Statement of Financial Activities

For the Year Ended 31 March 2006

	Note	Restricted £	Unrestricted £	2006 Total £	2005 Total £
<b>Incoming Resources</b>					
<i>Incoming Resources from Generated Funds:</i>	2				
Voluntary Income		-	80,864	<b>80,864</b>	131,003
Activities For Generating Funds		-	31,304	<b>31,304</b>	47,923
Investment Income		-	4,296	<b>4,296</b>	3,924
<i>Incoming Resources from Charitable Activities:</i>	3				
Family Support Services		15,312	3,772	<b>19,084</b>	33,957
Awareness Raising		-	-	-	-
<b>Total Incoming Resources</b>		<u>15,312</u>	<u>120,236</u>	<u><b>135,548</b></u>	<u>216,807</u>
<b>Resources Expended</b>					
<i>Costs of Generating Funds:</i>					
Fundraising & Merchandise Costs		1,928	11,818	<b>13,746</b>	15,457
<i>Charitable Activities:</i>					
Family Support Services		30,857	121,746	<b>152,603</b>	106,940
Awareness Raising		1,095	11,521	<b>12,616</b>	12,288
<i>Governance Costs</i>		514	7,048	<b>7,562</b>	8,462
<b>Total Resources Expended</b>	4	<u>34,394</u>	<u>152,133</u>	<u><b>186,527</b></u>	<u>143,147</u>
<b>Net Incoming / (Outgoing) Resources Before Transfers</b>	5	(19,082)	(31,897)	<b>(50,979)</b>	73,660
Transfers Between Funds		<u>231</u>	<u>(231)</u>	<u>-</u>	<u>-</u>
<b>Net Movement in Funds</b>		(18,851)	(32,128)	<b>(50,979)</b>	73,660
<b>Reconciliation of Funds</b>					
Total Funds Brought Forward		<u>22,146</u>	<u>115,136</u>	<u><b>137,282</b></u>	<u>63,622</u>
<b>Total Funds Carried Forward</b>		<u><b>3,295</b></u>	<u><b>83,008</b></u>	<u><b>86,303</b></u>	<u>137,282</u>

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 13 to the financial statements.

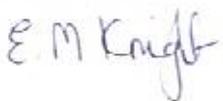
**The Rare Chromosome Disorder Support Group**

**Balance Sheet**

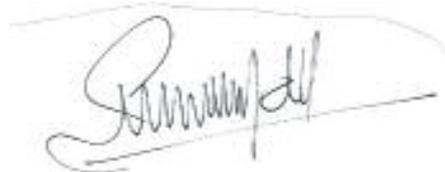
**As at 31 March 2006**

	Note	£	2006 £	2005 £
<b>Fixed Assets</b>				
Tangible Fixed Assets	8		<b>675</b>	1,013
Investments	9		<b>1,400</b>	-
			<b>2,075</b>	1,013
<b>Current Assets</b>				
Debtors	10	<b>2,350</b>		3,158
Cash at Bank and in Hand		<b>90,478</b>		137,399
		<b>92,828</b>		140,557
<b>Creditors: Amounts Due Within 1 Year</b>	11	<b>8,600</b>		4,288
<b>Net Current Assets</b>			<b>84,228</b>	136,269
<b>Net Assets</b>	12		<b>86,303</b>	137,282
<b>Funds</b>				
Restricted Funds	13		<b>3,295</b>	22,146
Unrestricted Funds:				
General Funds			<b>83,008</b>	115,136
<b>Total Funds</b>			<b>86,303</b>	137,282

Approved by the trustees on 1 July 2006 and signed on their behalf by



Edna Knight



Gillian Manvell

## The Rare Chromosome Disorder Support Group

### Notes to the Financial Statements

For the Year Ended 31 March 2006

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#### 1. Accounting Policies

- a) The financial statements have been prepared under the historical cost convention and in accordance with applicable accounting standards and the Charities Act 1993. They follow the recommendations in the Statement of Recommended Practice, Accounting and Reporting by Charities (issued in March 2005).
- b) Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when receivable.
- c) Revenue grants are credited to the Statement of Financial Activities when received or receivable whichever is earlier, unless they relate to a specific future period, in which case they are deferred.
- d) Resources expended are recognised in the period in which they are incurred. Resources expended include attributable VAT which cannot be recovered.
- e) Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment	4 years
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Items of equipment are capitalised where the purchase price exceeds £500.

- f) Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.
- g) Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.
- h) Transactions in foreign currencies are translated at rates prevailing at the date of the transaction. Balances denominated in foreign currencies are translated at the rate of exchange prevailing at the year end.

## 2. Incoming Resources From Generated Funds

	Restricted £	Unrestricted £	2006 Total £	2005 Total £
<i>Voluntary Income:</i>				
Health Foundation Grant	-	18,200	<b>18,200</b>	18,200
Garfield Weston Foundation Grant	-	-	-	75,000
Lloyds-TSB Foundation	-	-	-	5,200
London Law Trust Grant	-	-	-	2,000
Donated Services *	-	34,520	<b>34,520</b>	-
Donated Picture (see note 9)	-	1,400	<b>1,400</b>	-
General Donations	-	17,288	<b>17,288</b>	18,862
Overseas Donations	-	1,990	<b>1,990</b>	2,948
Covenants	-	2,976	<b>2,976</b>	1,736
Gift Aid	-	3,035	<b>3,035</b>	5,328
Collection Boxes	-	797	<b>797</b>	456
Little Yellow Book	-	29	<b>29</b>	65
Give As You Earn	-	629	<b>629</b>	1,208
<i>Total Voluntary Income</i>	-	80,864	<b>80,864</b>	131,003
<i>Activities For Generating Funds:</i>				
Fundraising Activities	-	27,993	<b>27,993</b>	44,715
Christmas Card & Merchandise Sales	-	3,311	<b>3,311</b>	3,208
<i>Total Activities For Generating Funds</i>	-	31,304	<b>31,304</b>	47,923

\* From 1 April 2005 the charity has included donated services in the accounts. The services have been valued at the estimated price for equivalent services that the charity would have paid in the open market. Equivalent amounts have been included as expenditure under the appropriate headings in the Statement of Financial Activities.

Donated services consist of the following:

Website & database design, development & maintenance	19,600
Professional verification of information in the charity's publications	14,400
Artwork and design of new charity stationery	400
Creche services at conference	120
<b>Total Donated Services</b>	<b>34,520</b>

### 3. Incoming Resources From Charitable Activities

	Restricted £	Unrestricted £	2006 Total £	2005 Total £
<i>Family Support Services:</i>				
EU Grant - SAFE Project	-	-	-	16,978
BBC Children in Need	10,315	-	<b>10,315</b>	8,551
VICTA	4,290	-	<b>4,290</b>	6,013
K U Leuven R&D - Eurogentest Project	707	-	<b>707</b>	2,415
Conference Income	-	<u>3,772</u>	<b><u>3,772</u></b>	-
<i>Total Income for Family Support Services</i>	<u>15,312</u>	<u>3,772</u>	<b><u>19,084</u></b>	<u>33,957</u>

The Rare Chromosome Disorder Support Group

Notes to the Financial Statements

For the Year Ended 31 March 2006

4. Total Resources Expended

	-----Family Support Services-----								
	Fundraising & Merchandise Costs £	Magazine, Website, Helpline & Conference £	Database £	Information Project	Indirect Family Support by Professionals	Awareness Raising £	Governance Costs £	2006 Total £	2005 Total £
Staff Costs (Note 6)	5,795	24,836	6,623	23,181	9,935	8,279	4,139	82,788	79,093
Postage	648	7,997	866	324	324	648	-	10,807	18,580
Printing & Stationery	909	11,210	1,212	455	455	909	-	15,150	22,239
Subscriptions & Licences	3,606	722	722	722	722	722	-	7,216	7,674
Travel	232	233	233	233	233	232	-	1,396	1,018
Meetings	-	-	-	-	-	-	800	800	1,575
Equipment	297	300	300	300	300	297	-	1,794	2,302
Merchandise	729	-	-	-	-	-	-	729	2,471
Training	119	118	118	118	118	118	-	709	160
Telephone & Internet	304	303	303	303	303	304	-	1,820	2,225
Legal & Professional	-	-	-	-	-	-	2,623	2,623	2,932
Website & Database Development	980	13,720	3,920	-	-	980	-	19,600	-
Conference	-	9,283	-	-	-	-	-	9,283	350
Hardbooks	70	70	70	70	70	70	-	420	937
Information Project	-	-	-	14,400	-	-	-	14,400	-
SAFE Project Expenses	-	11,766	-	3,922	-	-	-	15,688	1,022
Eurogentest Project Expenses	-	966	-	-	-	-	-	966	231
Depreciation	57	56	56	56	56	57	-	338	338
<b>Total Resources Expended</b>	<b>13,746</b>	<b>81,580</b>	<b>14,423</b>	<b>44,084</b>	<b>12,516</b>	<b>12,616</b>	<b>7,562</b>	<b>186,527</b>	<b>143,147</b>

# The Rare Chromosome Disorder Support Group

## Notes to the Financial Statements

For the Year Ended 31 March 2006

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### 5. Net Movement in Funds

This is stated after charging:

	<b>2006</b>	2005
	£	£
Depreciation	<b>338</b>	338
Trustees' indemnity insurance	<b>1,575</b>	1,575
Trustees' reimbursed expenses	<b>Nil</b>	Nil
Auditors' remuneration:		
▪ Statutory Audit	<b>2,115</b>	1,763
▪ Grant Audits	<b>646</b>	-
	<u><b>646</b></u>	<u>-</u>

### 6. Staff Costs and Numbers

Staff costs were as follows:

	<b>2006</b>	2005
	£	£
Salaries and Wages	<b>75,702</b>	72,536
Social Security Costs	<b>6,586</b>	6,557
Casual Staff	<b>500</b>	-
	<u><b>82,788</b></u>	<u>79,093</u>

No employee earned more than £60,000 during the year.

	<b>2006</b>	2005
	No.	No.
Average number of employees (full-time equivalent)	<u><b>4</b></u>	<u>4</u>

### 7. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

## 8. Tangible Fixed Assets

	Total £
<b>Cost</b>	
At 1 April 2005	1,351
Additions in year	<u>-</u>
At 31 March 2006	<u>1,351</u>
<b>Depreciation</b>	
At 1 April 2005	338
Charge for the year	<u>338</u>
At 31 March 2006	<u>676</u>
<b>Net Book Value At 31 March 2006</b>	<u><u>675</u></u>
At 31 March 2005	<u><u>1,013</u></u>

## 9. Investments

	2006 £	2005 £
Artwork	<u>1,400</u>	<u>-</u>

During 2005 Tracey Emin donated 2 pictures to the charity. Two professional valuations of the pictures were obtained and the pictures have been included in the accounts at the average of these valuations. The trustees have no immediate plans to sell the pictures, consequently they have been reported as fixed asset investments.

## 10. Debtors

	2006 £	2005 £
Prepayments	1,576	1,797
Other Debtors	<u>774</u>	<u>1,361</u>
	<u><u>2,350</u></u>	<u><u>3,158</u></u>

**11. Creditors : Amounts Due Within 1 Year**

	2006 £	2005 £
Accruals	2,115	1,763
Other Taxation & Social Security	1,970	1,991
Other Creditors	<u>4,515</u>	<u>534</u>
	<u><b>8,600</b></u>	<u><b>4,288</b></u>

**12. Analysis of Net Assets Between Funds**

	Restricted Funds £	Unrestricted Funds £	Total Funds £
Tangible Fixed Assets	-	675	<b>675</b>
Investments	-	1,400	<b>1,400</b>
Current Assets	3,295	89,533	<b>92,828</b>
Current Liabilities	<u>-</u>	<u>(8,600)</u>	<u><b>(8,600)</b></u>
<b>Net Assets at 31 March 2006</b>	<u><b>3,295</b></u>	<u><b>83,008</b></u>	<u><b>86,303</b></u>

**13. Movements in Funds**

	At 1 April 2005 £	Incoming Resources £	Outgoing Resources £	Transfers Between Funds £	At 31 March 2006 £
<b>Restricted Funds</b>					
VICTA	-	4,290	(4,290)	-	-
BBC Children in Need	1,435	10,315	(10,879)	-	<b>871</b>
Lloyds-TSB Foundation	2,571	-	(2,571)	-	-
SAFE Fund	15,956	-	(15,688)	-	<b>268</b>
Eurogentest Fund	<u>2,184</u>	<u>707</u>	<u>(966)</u>	<u>231</u>	<u><b>2,156</b></u>
<b>Total Restricted Funds</b>	<u>22,146</u>	<u>15,312</u>	<u>(34,394)</u>	<u>231</u>	<u><b>3,295</b></u>
<b>Unrestricted Funds</b>					
General Funds	<u>115,136</u>	<u>120,236</u>	<u>(152,133)</u>	<u>(231)</u>	<u><b>83,008</b></u>
<b>Total Unrestricted Funds</b>	<u>115,136</u>	<u>120,236</u>	<u>(152,133)</u>	<u>(231)</u>	<u><b>83,008</b></u>
<b>Total Funds</b>	<u><u>137,282</u></u>	<u><u>135,548</u></u>	<u><u>(186,527)</u></u>	<u><u>-</u></u>	<u><u><b>86,303</b></u></u>

### **13. Movements in Funds (continued)**

#### **Transfers Between Funds**

£231 was transferred from general funds to the Eurogentest Fund representing amounts charged to the Eurogentest Fund in 2004/5 that were subsequently funded by the charity's general funds.

#### **Purposes of Restricted Funds**

VICTA	To fund part of the Family Support Officer's salary
BBC Children in Need	To fund the Assistant Information Officer's salary
Lloyds-TSB Foundation	To fund the Finance & Administration Officer's salary
SAFE Fund	To fund all costs associated with the SAFE project
Eurogentest Fund	To fund all costs associated with the Eurogentest project

### **14. Post Balance Sheet Events**

The Rare Chromosome Disorder Support Group is a charitable trust and does not have limited company status. During the year the trustees decided to change the legal status of the organisation to a charitable company limited by guarantee.

The trustees set up a new limited company, called Rare Chromosome Disorder Support Group (company number 05460413), which was incorporated on 23 May 2005. This company was subsequently registered with the Charity Commission on 1 August 2005. The charitable company remained dormant from incorporation to its financial year end of 31 March 2006.

With effect from 1 April 2006, the charitable trust's assets and liabilities will be transferred to the new charitable company, and all of the charitable trusts activities will be operated through the new charitable company. The charitable trust will become dormant.